



Billing Code: 4163-18-P

DEPARTMENT OF HEALTH AND HUMAN SERVICES  
Centers for Disease Control and Prevention

[60Day-13-0469]

Proposed Data Collections Submitted for  
Public Comment and Recommendations

In compliance with the requirement of Section 3506(c)(2)(A) of the Paperwork Reduction Act of 1995 for opportunity for public comment on proposed data collection projects, the Centers for Disease Control and Prevention (CDC) will publish periodic summaries of proposed projects. To request more information on the proposed projects or to obtain a copy of the data collection plans and instruments, call 404-639-7570 or send comments to Kimberly Lane, 1600 Clifton Road, MS D-74, Atlanta, GA 30333 or send an email to [omb@cdc.gov](mailto:omb@cdc.gov).

Comments are invited on: (a) Whether the proposed collection of information is necessary for the proper performance of the functions of the agency, including whether the information shall have practical utility; (b) the accuracy of the agency's estimate of the burden of the proposed collection of information; (c) ways to enhance the quality, utility, and clarity of the information to be collected; and (d) ways to minimize the burden of the collection of information on

respondents, including through the use of automated collection techniques or other forms of information technology. Written comments should be received within 60 days of this notice.

### **Proposed Project**

National Program of Cancer Registries Cancer Surveillance System  
(OMB No. 0920-0469, exp. 11/30/2012) - Reinstatement - National  
Center for Chronic Disease Prevention and Health Promotion  
(NCCDPHP), Centers for Disease Control and Prevention (CDC).

### **Background and Brief Description**

One of every four deaths in the United States is attributable to cancer, making it the second leading cause of death among Americans. In 2009, over 1,500,000 people were diagnosed with invasive cancer and 650,000 people died of cancer. Living with cancer also affects many people. In January 2008, the National Cancer Institute estimated that 11.9 million Americans were alive with a history of invasive cancer.

In addition to the personal impact of cancer, the financial burden is also substantial. The direct treatment costs of cancer in 2008 have been estimated at \$93.2 billion, with additional indirect costs of \$134.9 billion in lost productivity due to illness and premature death.

In 1992, Congress passed the Cancer Registries Amendment Act, which established the National Program of Cancer Registries (NPCR). Through the NPCR, CDC provides support for state-based central cancer registries (CCR) that collect, manage, and analyze data about cancer cases in their jurisdictions. The CCR are responsible for obtaining diagnostic and treatment information from a variety of sources and for reconciling this information to produce accurate incidence and prevalence statistics. Through the NPCR, CDC also provides CCR with technical assistance that supports common standards for data definition and quality in a core set of data items. The NPCR-funded registries, which are located in states, the District of Columbia, and U.S. territories, have reported a standardized data set to CDC annually through the National Program of Cancer Registries Cancer Surveillance System (NPCR CSS) (OMB No. 0920-0469, exp. 11/30/2012). Many registries maintain additional data items that are not part of the standard NPCR CSS report to CDC.

The NPCR CSS has allowed CDC to collect, aggregate, evaluate and disseminate cancer incidence data at the national and state level. The NPCR CSS is the primary source of information for

*United States Cancer Statistics (USCS)*, which CDC has published annually since 2002. The latest *USCS* report published in 2012 provided cancer statistics for 98% of the United States population from all cancer registries whose data met national data standards. Prior to the publication of *USCS*, cancer incidence data at the national level were available for only 14% of the population of the United States.

CDC has also used information reported through the NPCR CSS to monitor cancer trends over time, describe geographic variation in cancer incidence throughout the country, and provide incidence data on minority populations and rare cancers. In addition, data on stage at diagnosis, type of treatment provided, and vital status allow CDC to assess progress in reducing morbidity and mortality from cancer. These activities and analyses further support CDC's planning and evaluation efforts for state and national cancer control and prevention. Finally, datasets compiled through the NPCR CSS have been made available to investigators for secondary analysis.

CDC plans to request OMB approval to reinstate the NPCR CSS information collection, with changes. First, the frequency of reporting to CDC will be changed from an annual to a semi-annual

schedule. The additional report will allow CDC to compile preliminary cancer incidence estimates in advance of the lengthy process of data validation required for each registry's final annual report. Second, data definitions for each report will be updated to reflect changes in national standards for cancer diagnosis, treatment, and coding. These changes will affect the standard reports for all NPCR-funded central cancer registries.

The third set of changes applies to a subset of 10 central cancer registries. These CCR received ARRA funding to develop common standards and reporting mechanisms for enhanced description of cases of breast cancer, colorectal cancer, and chronic myelogenous leukemia (CML). The enhanced data items will support more in-depth analysis of treatment strategies and patient outcomes than is currently possible with the standard NPCR CSS information collection. The 10 registries that participated in the enhancement process will begin reporting the additional data items to CDC in 2013 as part of their routine submission. CDC plans to make de-identified data available for comparative effectiveness research (CER).

OMB approval will be requested for three years. Respondents will be NPCR-supported central cancer registries in U.S. states, territories, and the District of Columbia. Information will be

reported electronically to CDC twice per year. The first report will consist of a single-year file for data that includes diagnoses 12 months past the close of the diagnosis year. The second report will consist of a cumulative file containing incidence data from the first diagnosis year for which the cancer registry collected data with the assistance of NPCR funds (e.g., 1995) through 24 months past the close of the diagnosis year (e.g., 2010 data submitted in 2012). The estimated burden per response is two hours. Because cancer incidence data are already collected, aggregated and used for analyses at the state level, the additional burden of reporting the information to CDC is small and the number of data items in the report does not affect the estimated burden per response. There are no costs to respondents except their time.

Estimated Annualized Burden Hours

Type of Respondents	Form Name	No. of Respondents	No. of Responses per Respondent	Average Burden per Response (in hours)	Total Burden (in hours)
Central Cancer Registries in States, Territories, and the District of Columbia	Standard NPCR CSS Report	38	2	2	152
	Enhanced NPCR CSS Report	10	2	2	40
	Total				192

Date: December 4, 2012

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Ron A. Otten,  
Director, Office of Scientific Integrity  
(OSI)  
Office of the Associate Director for Science  
(OADS)  
Office of the Director  
Centers for Disease Control and Prevention

[FR Doc. 2012-29722 Filed 12/07/2012 at 8:45  
am; Publication Date: 12/10/2012]